**A National Conversation to Inform a New Dementia Strategy**

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# About us

We’re RCOT, the Royal College of Occupational Therapists. We’ve championed the profession and the people behind it for over 80 years; and today, we are thriving with over 35,000 members. Then and now, we’re here to help achieve life-changing breakthroughs for our members, for the people they support and for society as a whole.

Occupational therapy helps you live your best life at home, at work – and everywhere else. It’s about being able to do the things you want and have to do. That could mean helping you overcome challenges learning at school, going to work, playing sport or simply doing the dishes. Everything is focused on increasing independence and wellbeing.

It’s science-based, health and social care profession that’s regulated by the Health and Care Professions Council.

An occupational therapist helps people of all ages overcome challenges completing everyday tasks or activities – what we call ‘occupations’. Occupational therapists see beyond diagnoses and limitations to hopes and aspirations. They look at relationships between the activities you do every day – your occupations – alongside the challenges you face and your environment.

Then, they create a plan of goals and adjustments targeted at achieving a specific set of activities. The plan is practical, realistic and personal to you as an individual, to help you achieve the breakthroughs you need to elevate your everyday life.

This support can give people a renewed sense of purpose. It can also open up new opportunities and change the way people feel about the future.

# Our response

1. What does dementia mean to you and those around you?

A diagnosis of dementia is a unique experience to each individual and it will be essential to the success of the strategy that lived experience of those living with dementia and their families are heard. Occupational therapists working with those with lived experience of dementia can provide an insight into the supports and interventions that allow people to live their best lives.

Consultation with RCOT members identified that for many a diagnosis of dementia can be a frightening and uncertain time. This can be exacerbated by the stigma surrounding dementia which can cause people to withdraw from their communities or prevent people coming forward for diagnosis at all. Dementia shouldn’t mean disengaging from doing what is important to you but being supported to continue to do what you need and want to do- but perhaps in a different way- with the support and advice of occupational therapists.

RCOT and its members feel strongly that fear and uncertainty can be reduced by ensuring access to the correct support at the correct time. Ongoing education at population level to challenge stigma surrounding dementia can reduce the uncertainty faced by many. It is important that holistic support that involves families and support networks is available from pre diagnosis to end of life. RCOT members report that many individuals are not aware of the support that they are entitled. They are also unaware of the benefits of rehabilitation when managing how to live with dementia.

1. What supports work well for you?

Occupational therapists are skilled health and social care professionals who can provide evidence-based support at all stages of the dementia journey. RCOT members report that practical support such as building routine and structure can make a significant difference to an individual’s wellbeing. Occupational therapists can support people to engage in meaningful daily activities such as cooking which can improve quality of life. Occupational therapists can assess homes to provide advice to reduce falls and visual prompts to support memory.

Occupational therapists work with people living with dementia in a range of settings including home, workplace, community, acute hospital, GP surgeries and care homes. Working in partnership and focusing on strengths and abilities, one key element of occupational therapists’ contribution is to identify and prioritise what is important to the person. The profession has a key role to play in the lives of people living with dementia and their supporters as their needs change. There is growing evidence underpinning occupational therapy within dementia prevention, diagnosis, post diagnostic support, integrated care, and the advanced stages of this condition.

Home based memory rehabilitation (HBMR) is an individualised intervention focusing on skills, everyday function, and occupation (McGrath 2013). HBMR integrates the key principles of a cognitive rehabilitation approach in the person’s own home (McGrath 2013). RCOT members highlighted the importance of moving to an early intervention approach- members recommended starting HBMR pre-diagnosis as part of a “waiting well” initiative as they report members often must wait a significant amount of time to gain an official diagnosis when the functional rehabilitation can improve their lives now. HBMR can benefit individuals with memory concerns even if it doesn’t result in a diagnosis of dementia. Intervening early can present opportunities for health promotion and identifying risk factors for vascular dementia, stroke etc. RCOT believe that those with mild cognitive impairments identified within GP surgeries should have access to cognitive rehabilitation e.g., HBMR. Mild cognitive impairment in primary care should be reviewed annually and RCOT would encourage earlier interventions for those effected.

‘Journeying through dementia’ is a peer-to-peer group intervention that supports participants in sharing knowledge, techniques and strategies that promote continued engagement in meaningful activity and communities (JTD 2022). Occupational therapists are well positioned to provide this intervention as it focuses on what is important to the individual and their strengths.

Occupational therapists can recommend and educate individuals and their families on equipment, adaptations and telecare options that can allow individuals to remain independent and safe within their own homes for as long as possible. This can provide individuals and their supporters reassurance and confidence in the home.

Occupational therapists can work with link workers, community rehabilitation teams and reablement teams to tailor support with a person-centred approach. Occupational therapists promote independence and engagement in the activities that are important to the individual. Keeping the person well for longer.

1. What challenges need to be addressed?

RCOT members report that delays to diagnosis and post diagnostic support is a significant challenge. Members report that teams are under resourced due to recruitment and retention issues across the workforce. A recent RCOT survey of the rehabilitation workforce found 71.4% of Scottish respondents believe their team doesn’t have sufficient staff to meet demand (RCOT 2022). Delays to support and diagnosis can impact the mental health and wellbeing of the individual and their support network during an already uncertain time.

RCOT members note that services can feel disconnected when individuals move between acute and community services, and it isn’t always clear who should prioritise the dementia support. All health and social care staff should have a level of training and education around dementia and how to best support individuals. RCOT members believe dementia should be everyone’s business. RCOT members report that individuals living with dementia can find traditional acute settings distressing and the unfamiliar environment and routines can make it difficult for individuals to function well. This also impacts the how individuals cope with occupational therapists’ functional assessments. Functional assessments should be carried out in individuals own environment where possible. This allows a more accurate understanding of how individuals manage day to day.

RCOT members report that citizens aren’t aware of the support they are entitled to, and many aren’t aware that rehabilitation can play a key role in supporting them to manage their condition and live their best life. Variations in teams and referral pathways across Scotland can make it difficult for individuals to navigate the available support. RCOT members also note that individuals have feelings of embarrassment around changes to cognition and memory; this can mean individuals delay coming forward for support or diagnosis.

* Early intervention is important to allow individuals to access rehabilitation, lifestyle advice and support as well as allowing the individual to be involved in future planning.
* Education for the public and for health and social care staff is essential to tackle the stigma surrounding dementia.
* Staff should take a strength-based approach to supporting those with dementia and empower them to remain independent for as long as possible.

Scotland’s new dementia strategy should align with Scotland’s wider public health agenda. Occupational therapists have the skills and expertise to contribute to public health messaging and education around self-management, brain health and living with dementia.

1. How would addressing these challenges change lives?

Improving waiting times to diagnosis and post diagnostic support will lead to improved outcomes for service users and a more positive experience for both service users and their support networks.

A push towards early intervention and prevention will improve outcomes at a population level. Early intervention will support individuals to live well for longer, maintain independence for longer and enhance feelings of control.

Improving public perception of dementia will reduce stigma around dementia and encourage individuals to come forward for support at an earlier stage of their journey. Reducing stigma will improve outcomes for those living with dementia as they would be less likely to withdraw and disengage from their communities and meaningful occupations.

Positioning occupational therapists where they can use their skillset to make a significant difference to individual outcomes at an early stage in the dementia journey may improve job satisfaction and improve overall staff recruitment retention and wellbeing.

1. What do we need to build on/learn from what has been done before?

Scotland should aim to adopt an early intervention and prevention approach to healthcare which includes effective public health information and education. Key messaging around brain health at a population level could play an important role in the prevention and early detection of dementia.

Occupational therapists have the skills and expertise to support individuals and all points of their dementia journey early intervention, prevention, diagnostic, post diagnostic support and end of life care. Occupational therapists can make a positive difference to service user outcomes when positioned within primary care. As well as improving access to occupational therapy, occupational therapists within GP surgeries are demonstrating their efficacy in providing self-management advice, rehabilitation, vocational rehabilitation and community engagement and safety. Further investment is required to ensure access to occupational therapists positioned in primary care across Scotland.

The Connecting People Connecting Support document from previous dementia strategies have led to innovations across Scotland such as the Journey through Dementia project in Inverclyde and self-management resources through third sector organisations e.g. Alzheimer Scotland. The Scottish Government should look to encourage the sharing of best practice and a once for Scotland approach to rehabilitation which includes psychological and occupational rehabilitation.

1. What else would you like to tell us?

Support for families and support networks throughout the stages of dementia from diagnosis to end of life should be prioritised to ensure loved ones are able to support those living with dementia to live their best lives. Support should also be available to the supporters of those living with dementia to assist them to adjust to their new role and changes to their own routines which can be distressing. Occupational therapists have the expertise to work alongside people to understand their daily lives and promote them to stay active.

References

[McGrath M P 2013 Promoting safety in the home: The home-based Memory Rehabilitation Program for persons with mild Alzheimer’s disease and other dementias](http://patientsafety.health.org.uk/sites/default/files/resources/promoting_safety_in_the_home.pdf).

Journey through dementia (JTD) 2022. [About — Journeying Through Dementia (jtd.org.uk)](https://www.jtd.org.uk/about-us) [Accessed online 1/12/2022]

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